

response to areas of identified need. Importantly, proposed interventions are tailored to the capacities of the individual treatment centres. This increases the likelihood of the adoption of the overall strategy for care without requiring substantial additional resources.

The articles by Butow and Turner describe the evidence base for interventions to improve the psychosocial outcomes for patients, including an emphasis on the importance of effective communication and on the provision of support as outlined in the National Health and Medical Research Council's recently released *Psychosocial Clinical Practice Guidelines*.

Finally, two specific models of cancer care are described in the articles by Luxford et al. and Burton et al. The first is a demonstration project of the effect, cost, and acceptability of multidisciplinary cancer care in Australia. In this, the Year of the Volunteer, the following paper by Burton et al. emphasises the

important and growing role of volunteers in providing a support service for women with breast cancer in NSW, as part of The Cancer Council NSW's Breast Cancer Support Service.

While there is now a growing acceptance that supportive care is as important as clinical treatment in the overall management of cancer, the challenge will be to ensure that the provision of evidence based supportive care remains on the agenda of both health professionals and decision makers. ■■

A copy of *Optimising Cancer Management—A Cancer Care Model for NSW*, and other reports in this cancer care series, can be downloaded from the NSW Department of Health's Web site at www.health.nsw.gov.au.

AREA CANCER CONTROL NETWORK: FROM COTTAGE INDUSTRY TO STRATEGIC CARE

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The South Western Sydney Area Health Service (SWSAHS) serves a population of three quarters of a million people. This population experiences comparatively high levels of social disadvantage, is drawn from a diverse multicultural background, and is geographically dispersed through urban, semi-rural, and rural localities. The SWSAHS is committed to cancer prevention and to improving treatment outcomes and service satisfaction for patients with cancer. This article describes two of the many initiatives underway for the local implementation of the Area Cancer Control Network, an approach to cancer services based on the recommendations from the *Optimising Cancer Management Initiative—Final Report to the Expert Advisory Group*.¹

OVERVIEW

There is a considered view, and some evidence, that improving the delivery of cancer services will subsequently improve both the clinical outcomes for patients and organisational efficiency.^{2,3,4} The perception that health services are complex systems arises in part from the difficulty in obtaining a basic prerequisite for good management: namely, good information. Nowhere is this more obvious than in the current

management of cancer services. The challenge to implementing *Optimising Cancer Management—A Cancer Care Model for NSW*,⁵ or the Area Cancer Control Network as it is locally known, is the paucity of robust organisational and clinical information to support planning and management within the SWSAHS, or to enable outcomes and efficiencies between area health services to be compared.^{6,7}

The priority of the Area Cancer Control Network strategy has been to develop two implementation frameworks. The first is for an Area Clinical Cancer Information System (ACCIS) to capture both clinical and organisational data (Figure 1). The second is a comprehensive planning framework to guide the required structural and management changes. Cancer services will be organised around the nine common cancer tumour sites—such as breast, colo-rectal, and lung—using the planning framework.

INFORMATION SYSTEM FRAMEWORK

The first step in developing the ACCIS is to establish an area clinical cancer registry. Cancer services are poorly informed of outcomes linked to particular types of treatment, such as treatment-specific survival rates and the long-term effect of treatments that for many survivors of cancer may include serious physical and psychosocial morbidity.^{8,9} The benefits of area-based clinical cancer registries are evident in the work of the Ontario and British

Columbian Registries where it has been possible to demonstrate the organisational effects of cancer service delivery on patient outcomes.¹⁰

In NSW, the central registry system does not collect clinically relevant staging information, descriptions of local treatment regimens, or outcome data. The lack of this information is a significant impediment to improving the safety and quality of cancer services. Implementing an area-based clinical cancer registry was identified as integral to the success of Area Cancer Control Networks.^{11,12,13} The particular advantage of area-based clinical cancer registries will be the capture of clinical data describing radiotherapy and chemotherapy treatments, which are most often delivered on an outpatient basis and, unlike surgery, are only reported in aggregate form.

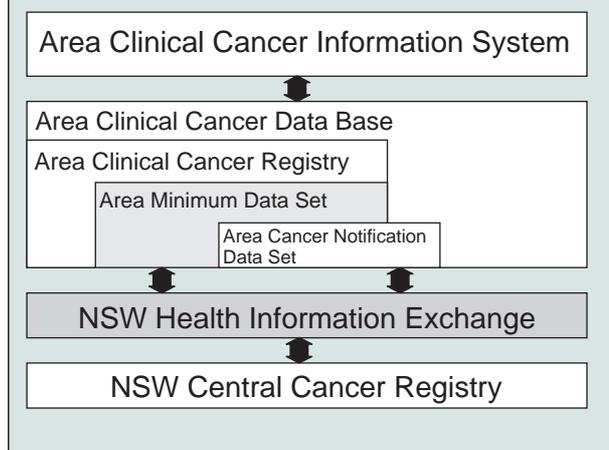
To support area-based clinical cancer registries a minimum data set, data dictionary, and business case have been developed by the NSW Department of Health as part of the recommendations in the *Optimising Cancer Management* report.⁵ This initiative will still require funding for it to be implemented in the major teaching hospitals, and to enable the exchange of data between the area health services.¹

In SWSAHS, a locally-funded plan has been developed to implement the area-based clinical cancer registry. This required teasing out the relationship between at least 14 other information technology initiatives arising from local, state and national health portfolios. Some of these are the:

- Radiation and Medical Oncology Information Management and Technology Plan;
- Patient Administration Systems Project;

FIGURE 1

AN AREA CLINICAL CANCER INFORMATION MODEL

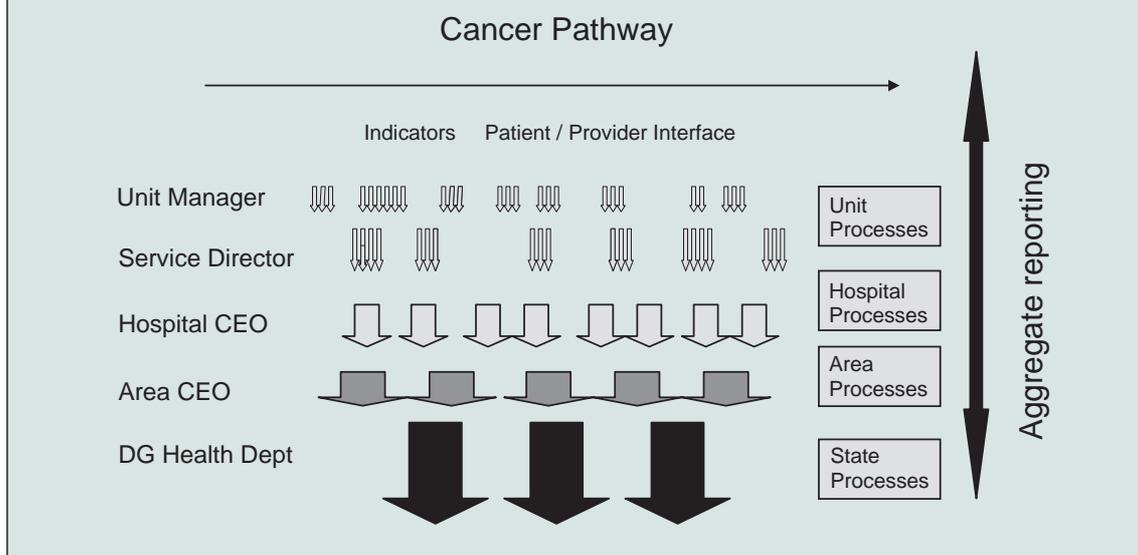


- Clinical Information Systems (Point of Care) Project;
- Community Based Health Information Development Project;
- Cancer Clinical Data Model;
- Health Information Exchange;
- NSW Central Cancer Registry Information Management and Technology Strategy.

The proposed Radiation Information Management System is the logical backbone for an area-based clinical cancer registry.^{12,13} However, until it is implemented, the Surgical Audit Database—developed by the Division of Surgery at the Liverpool Health Service—is a suitable alternative and an invaluable precedent for solutions to both technical

FIGURE 2

SCALABILITY REPORTING SYSTEM



and local governance issues. The area-based clinical cancer registry must also be able to collect data from private pathology laboratories, hospitals, and service providers. For both patients and service providers, a satisfactory resolution needs to be found to the significant and topical issue of consent, privacy, and confidentiality.¹⁴ It is uncertain whether the transfer of patient identified information from private service providers to an area-based clinical cancer registry will be obligatory, discretionary, or even legal.

A three-staged plan has been developed to guide the complex task of implementation across multiple sectors and service providers both public and private. The area-based clinical cancer registry must be embedded into the information and technology plan of the area health service, to ensure that it is integrated with other information and technology initiatives of the area, and not be left as a stand-alone initiative. The three stages are to:

- pilot the collection of the minimum data set at Liverpool Health Service and develop the business case for the optimal system architecture and governance structure;
- establish a fully working registry at one pilot site;
- sequentially deploy the system throughout the public and private services in the area.

Ideally, to avoid duplication and incompatibility of data definitions and storage, it is critical to develop a system that is uniform across NSW. In the absence of a strategic central approach we advocate forming data alliances between the area health services.

KEY PERFORMANCE INDICATORS AND TUMOUR SITE GROUPS

For quality improvement in clinical practice the area-based clinical cancer registry must develop and incorporate key performance indicators, as well as a scalable reporting system for these indicators. A scalable reporting system is one with the ability to interrogate and aggregate key performance indicators generated at multiple levels of organisational and clinical activity: state, area, hospital and clinic. Without the capacity of an information system to condense data while maintaining the integrity of the original source, the volume and complexity of information generated from multiple sites and service providers becomes overwhelming and the benefits cannot be fully realised (Figure 2).

Management of the Area Cancer Control Network has been organised along cancer tumour sites for the nine common cancers. This structure acknowledges the different needs, volumes of patients, and service plans required for each group of cancers. Acute care clinicians with a specific professional interest have been appointed as tumour site leaders to implement evidence based clinical protocols, provide policy advice to the area, and develop key performance indicators to monitor quality, measure

activity, describe treatment outcomes, and establish benchmarking. It is expected that standing reports of the key performance indicators developed for the service will be generated from the Area Clinical Cancer Registry for action by these groups.

It is proposed that each tumour site leader will build upon existing professional interest groups and extend them to include multi-disciplinary representation. It is envisaged that each group will develop service plans within the planning framework encompassing the full range of cancer services from health promotion, screening, diagnosis, treatment, palliation and support services. There is no expectation of additional resources to support cancer services, therefore existing resources must be identified for reallocation. Finding sufficient management and clerical resources to support these groups is also problematic.

CONCLUSION

The area-based cancer control network can only be validated by the collection of data, and this establishes accurate information as the cornerstone of cancer services. By implementing an area-based clinical information system it will be possible to assess clinical and organisational outcomes and use the information for all aspects of quality improvement. The benefits of information can only be realised if action is possible. The tumour site leaders and multi-disciplinary groups will monitor their own key performance indicators and are responsible for responding to ensure the best value and outcomes for their service. Regardless of structural and management differences the common element for all area health services is the need to develop good clinical and organisational information systems.

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CANCER PATIENTS' SUPPORTIVE CARE NEEDS: STRATEGIES FOR ASSESSMENT AND INTERVENTION

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This article describes some of the work undertaken over the last decade by The Cancer Council NSW—through the Cancer Education Research Program (CERP) and the Cancer Services Unit—to measure the supportive care needs of cancer patients, and identify effective strategies for attending to these needs as part of routine clinical practice.

Cancer is a major cause of morbidity and mortality throughout the world, with nine million people newly diagnosed each year and five million people dying from the disease.¹ In Australia, cancer is the second most common cause of death, accounting for approximately one quarter of all deaths.² Approximately 55,000 cases of cancer are diagnosed each year, the most common being cancers of the breast, prostate, colon–rectum, lung, and melanoma. Due in part to the focus on early detection and improved clinical management of cancer, five-year survival rates indicate that more people are now living with cancer, and for longer periods of time.^{1,3}

Most cancer patients now undergo a combination of effective—but nonetheless traumatic—treatments such as the surgical removal of the cancer, radiotherapy, chemotherapy, and hormone therapies. Although these treatments have the potential to cure some cancers, and to prolong the lives of patients with other cancers, they are associated with a wide range of physical and psychosocial problems. The psychosocial morbidity experienced by cancer patients has been estimated using a number of different strategies including the assessment of quality of life; satisfaction with care; and, more recently, needs assessment. Quality of life research has indicated that the diagnosis and subsequent treatment of cancer impairs cancer patients' work and social activities, management of the home, family and other relationships, sleep patterns, and sexual activity.^{4–7} In addition, studies exploring the

psychological sequelae of cancer have suggested that cancer patients experience clinically significant levels of anxiety and depression.^{5,7–13}

Although both cancer specialists and patients may accept physical and psychosocial problems as an inevitable part of the disease and its treatment,^{14,15} these problems can have a substantial affect on cancer patients' compliance with their treatment and with outcomes. For example, it has been estimated that up to one-third of patients will abandon chemotherapy prematurely as a result of the physical and psychosocial symptoms, despite the potentially life-threatening consequences of such action.¹⁶ Therefore, it is important for cancer specialists to be aware of the prevalence of such problems among their cancer patients and to do their best to prevent them where possible or to address them when they occur.

The routine assessment of cancer patients' unmet needs in the clinical setting has the potential to quickly identify issues of concern for the patient, which can then be brought to the attention of the treatment team for appropriate intervention. In contrast to assessments of satisfaction and quality of life, needs assessments directly assess and identify specific issues for patients, as well as the perceived magnitude of those needs. In this context, 'needs' can be defined as the requirement of some action or resource that is necessary, desirable or useful to attain optimal well-being.¹⁷ Needs assessment enables individuals—and sub-groups of patients with higher levels of needs—to be identified and targeted with appropriate early interventions; and allows those aspects of health services that require improving to be identified and prioritised.¹⁸

Research on the needs of patients with cancer has identified high levels of unmet need and a difference in the types of unmet needs depending on the cancer population studied. For example, high levels of unmet need in the provision of information have been reported in studies with different types of cancer